Long COVID activities and results in the EU and the US
Background document for the 13 December 2022 EU-US Long COVID conference

The motivation behind an EU-US Long COVID conference and its objectives

Now that the centre of the COVID-19 pandemic storm has passed, both the European Union and the United States are facing the challenges of Long COVID. Anthony Fauci, Director of the US National Institute of Allergy and Infectious Diseases, referred to the condition as an ''insidious' public health emergency'. Both EU and US health systems are still largely groping in the dark when it comes to the treatment and potential impact of Long COVID.

As both the EU and the US have recently initiated research and response activities, it is this stage in which mutual learning can be most helpful in developing an effective and joined response to this major health challenge. **The objectives of this conference are therefore:** 1) to exchange experiences and knowledge between the EU and the US in Long COVID research, treatment and health systems' responses; 2) to identify key challenges and knowledge gaps in these areas.

Definitions, prevalence and treatment of Long COVID/Post COVID-19 condition

There is a large variety in terms that are used for the health problems that some people experience in the months after a COVID-19 infection, including: Long COVID, long-haul COVID, post-COVID-19 condition, chronic COVID, and post-acute sequelae of SARS-CoV-2 (PASC).

Besides a verity in terms, there is not one unifocal definition of Long COVID, see for instance the draft Opinion of the European Commission Expert Panel on Long COVID. The World Health Organization defines post-COVID-19 condition as an illness that occurs in people who have a history of probable or confirmed SARS-CoV-2 infection, usually within three months from the onset of COVID-19, with symptoms and effects that last for at least two months. The symptoms and effects of post COVID-19 condition cannot be explained by an alternative diagnosis. Symptoms and effects often include fatigue, breathlessness, muscle aches and cognitive dysfunction (for example, confusion, forgetfulness, or a lack of mental focus and clarity).

It has been estimated that approximately 10%-20% of people that were infected by SARS-CoV-2 develop Long COVID. At least 17 million people in the WHO European Region experienced Long COVID in the first two years of the pandemic. In the United States, the Household Pulse Survey (HPS) report of the Census Bureau showed that in June 2022, around 16 million working-age Americans (aged 18 to 65) had Long COVID. Crucially, the prevalence rate of Long COVID can be difficult to establish given the temporal separation between infection and Long COVID symptoms, and the presence of multimorbidity, as highlighted in a recently published ECDC systematic review.

Health system reactions to Long COVID

In the EU, countries have responded in different ways and speed to Long COVID. The PHIRI project showed that in early 2022, the Netherlands, Germany, Poland, Czech Republic, Slovenia, and Norway had planned processes for a coordinated management of Long COVID, including for instance medical guidelines for diagnosis and treatment. At that time, Portugal, Italy, Slovakia, and Ireland had partially planned processes for coordinated management. Only Sweden had a Long COVID registry. In another study, it has been reported that in some EU countries specialist Long COVID clinics have been set up, including Belgium, France, Germany and Spain.

In the US, the Biden–Harris Administration released the Services and Supports for Longer-Term Impacts of COVID-19 report, which describes the federally funded supports and services currently available to those who experience long-term effects of COVID-19. In the US, several post-COVID care clinics were launched during the pandemic, where Long COVID patients can be treated.

Research activities and gaps in knowledge

Not enough is known about the clinical manifestations, risk factors and underlying mechanisms of Long COVID. Under the Horizon Europe funding programme, a number of studies are currently taking place, including the ORCHESTRA project, the unCoVer project and the Long COVID project. An overview of clinical trials on Long COVID can also be identified via the European Union Clinical Trials Register.
Within the US, the National Research Action Plan on Long COVID acknowledges that research is urgently needed to unravel the biological mechanisms that underpin the symptoms and conditions attributed to Long COVID and to develop evidence-based treatments for them. One of the main research activities in the US is the RECOVER Initiative, initiated by the National Institutes of Health (NIH). RECOVER research aims to understand why some people develop Long COVID and is preparing several clinical trials across the US to evaluate treatments to improve Long COVID symptoms.

Potential impact of Long COVID on health systems and society in EU and US

During the hearing of the US congress in July 2022 on Understanding and Addressing Long COVID and Its Health and Economic Consequences, the urgency for action on Long COVID was stressed, because of the long-term health and economic burden.
Long COVID can potentially have a huge impact on health systems in two areas, the health workforce potentially developing Long COVID, and the care of patients with Long COVID. Health workers have been at particular risk of contracting COVID-19 and, consequently, of developing Long COVID.
Besides the impact on health systems, Long COVID can potentially have a major impact on labour markets. A study published in The Lancet found that 22% of people with Long COVID were unable to work due to ill health, and another 45% had to reduce hours worked.
The Household Pulse Survey (HPS) report showed that in the US, 2 to 4 million working-age Americans are out of work due to Long COVID. The annual cost of those lost wages alone is around $170 billion a year (and potentially as high as $230 billion). The decreased productivity from people working with symptoms such as severe fatigue are not taken into account in these numbers.

Closing remarks

This background document has set the scene for the Long COVID conference to be held on 13 December 2022. It includes links to relevant reports and activities that could be read in preparation of participation in the conference.